The Good Road Home

How Hoosiers Feel About Home Care Services for Senior Citizens and Persons with Disabilities

August 2011

THE GENERATIONS PROJECT

Acknowledgments

The Governing Board of The Generations Project would like to acknowledge the special contributions made by individuals and institutions that made this publication possible, and *The Good Road Home* conference of January 13, 2011 on which this report is based.

The **Retirement Research Foundation** (RRF) in Chicago, Illinois, which was the major underwriter of the Project for nearly five years, funded the Project's Round Table Education Series (RTES) in 2007, 2008, and 2009. That series of local, regional and statewide meetings, including over 700 citizens, established the foundation for the consensus conclusions reached at the January 13th conference in Indianapolis. The RTES meetings were used as advocacy education training sessions for citizens that deal with the challenges of home and community-based services (HCBS) in their daily lives. The RTES meetings were also the means for the Project to learn firsthand from HCBS consumers, their family caregivers, HCBS providers, local officials, senior citizens, persons with disabilities, and members of the business community. The attendees in the January 13th conference were recruited directly from the participants in the RTES meetings. The knowledge gained from the RTES meetings was published in two important Project reports: *Lessons from Home* (2008) and *Lessons from Home Applied* (2010). Without the support of the Retirement Research Foundation these pivotal meetings and publications would not have been possible.

The **Lilly Grant Office** (in Kalamazoo, Michigan) of Eli Lilly & Company and the **Service Employees International Union** (SEIU) have given important and timely support to the Project. Lilly and SEIU were the major underwriters of the January 13th conference and have generously supported past education conferences of The Generations Project.

While RRF, Lilly and SEIU are substantially different institutions they have shared common values in their support of The Generations Project. They have asked us to engage citizens in true learning opportunities, to fairly represent the views of citizens participating in advocacy education and training activities, and to promote positive discourse among citizens seeking solutions to the pressing problems associated with long term care. The Project has been honored to accept the support of these entities and has sought to fulfill the above expectations.

Without a doubt the bulk of our thanks should go to the 700 citizens that have participated in the Project's Round Table Education Series, culminating with The Good Road Home Conference of January 13, 2011. These citizens are the real story of the report that follows. They have met the difficult challenges associated with the need and use of home and community-based services. In doing that they have been willing to share their experience and wisdom with others with the hope of improving and enhancing the availability of HCBS in Indiana. Their collective goal is the establishment of a long-term care system that allows each and every Hoosiers who wants and needs home care to receive that care without the fear of being forced into an institution.

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Executive Summary: The Good Road Home

Seventy Hoosiers took part in *The Good Road Home* conference on home and community-based services for senior citizens and persons with disabilities that was held in downtown Indianapolis on January 13, 2011. The conference was the culmination of the Round Table Education Series on long term care reform that began in 2007 and was hosted by The Generations Project. With the exception of some lawmakers, the January 13th participants had previously taken part in the education series meetings that were held throughout the state.

Kathy Leitch

The main presenter at the conference was Kathy Leitch, who retired as the Assistant Secretary, Aging and Disability Services Administration, Department of Social and Health Services for the State of Washington on December 31, 2010, where she directed that state's nationally regarded long term care system. Secretary Leitch directly compared the Washington long term care system with like services in Indiana. She demonstrated that Washington, by reducing the use of publicly funded nursing home care and using those savings to grow home and community-based services, was able to dramatically expand the availability of the latter services, improve nursing home quality, and generate surplus dollars to fund other programs, such as public education. Secretary Leitch also noted that Indiana could be at risk of corrective action by the U.S. Department of Justice because the state's extreme bias in favor of institutional care. (See items #10 and #11 below.)

The January 13th participants reached the following consensus conclusions regarding home and community-based services in Indiana.

1. Indiana should be expanding the use of home and community-based services in order to solve its Medicaid spending crisis.
2. Indiana's Medicaid spending crisis is a direct result of over-using expensive nursing home care and under-utilizing lower cost and higher quality home and community-based care.
3. The CHOICE home care program is the lowest cost, most cost efficient, most popular, and best publicly funded home care program in Indiana.
4. The CHOICE program should be expanded to reduce the state's over-utilization of Medicaid funded nursing home care.
5. CHOICE should be fully funded at the $48.675 million level, CHOICE funds withheld by state should be restored to that program, CHOICE funds should not be used for Medicaid waiver match because that reduces the overall public investment in home care and contributes to the over-utilization of nursing home care, and all CHOICE users should have equal access to individual and agency-based providers.
6. The Medicaid aged and disabled waiver program should be expanded, and state dollars for Medicaid match secured by using the savings that are generated by reducing the over-

utilization of Medicaid nursing home care. This "self-funding" mechanism has been used by other states to cut Medicaid costs while expanding and improving home and community-based services. It should also include equal access by consumers to individual and agency based providers.

7. Savings generated by using more home and community-based services, while concurrently reducing the over-use of Medicaid funded nursing home care, should also be used to increase the quality of care for persons who remain in nursing homes.
8. Indiana should encourage and assist nursing home providers in transitioning to other forms of long term care and through well planned reductions in nursing home utilization.
9. Indiana is growing its investment in publicly financed nursing home care while most states are doing the opposite and investing in home and community-based services in order to save money, to serve more people, and to produce better long term care outcomes.
10. Washington state has a population of 6.6 million people but has only 10,600 individuals per day in Medicaid funded nursing home care because it has expanded the use of home and community-based services and has saved money by doing so. Indiana has a population of nearly 6.4 million people and a Medicaid nursing home daily census of over 28,500 people because it has failed to grow long term care options. With virtually identical levels of total long term care spending, Indiana serves only 14,000 individuals per day through its CHOICE and Medicaid aged and disabled waiver programs while Washington serves 45,000 persons in comparable home and community-based services.
11. Indiana's failure to grow publicly financed home and community-based service options, while letting waiting lists soar for the CHOICE and Medicaid aged and disabled waiver, is making the state vulnerable to litigation. The U.S. Department of Justice is presently warning states it is prepared to take legal action if necessary against any state that refuses to provide home and community-based services as needed by its citizens and as stipulated by the U.S. Supreme Court in the Olmstead case.
12. Indiana is developing a reputation as a bad living and employment destination for individuals with disabilities, adults with disabilities, and their families. Corporations that value their employees are increasingly concerned with Indiana's lack of investment in home and community-based services.
13. Indiana continues to harm individuals with brain injury and other disabilities by continuing to block access to publicly financed home and community-based services, and continues to drive people out of state in order to get needed services.
14. Indiana's privatized welfare system continues to harm its citizens including senior citizens and persons with disabilities who need access to home and community-based services.
15. The findings of The Generations Project through its Round Table Education Series in 2008 and 2010 should still be implemented by the state, and include real economic opportunities for business, industry, and the citizens of the state. Those findings are on the Project's website at www.generationsproject.org.

The Good Road Home

How Hoosiers Feel About Home Care Services for Senior Citizens and Persons with Disabilities

Mission and Goals

The mission of The Generations Project is to re-balance Indiana's long term care (LTC) system and to empower the citizens that use long term care services so they can play a positive role in the development of public policy. The Project believes the lack of citizen engagement has contributed to the state's substantial over investment in nursing homes (NHs) and similar institutions, and to its dramatic under investment in home and community-based services (HCBS). Correcting this imbalance in the long term care system lies at the heart of the Project's mission. Empowering the users of long term care is essential if re-balancing is to be achieved. When that happens the measures of a re-balanced system will includes several times more citizens using publicly financed HCBS than NH care, vastly improved care in the NHs that remain, and a long term care system as a whole that is defined and driven by the consumers of LTC.

The Good Road Home conference on January 13, 2011 had three goals. One, to complete The Generations Project's Round Table Education Series, which was started in 2007 to educate and empower citizens in communities throughout Indiana. That process included long-term care issues, how to grow the public investment in HCBS, and how to participate in civic life in a manner that directly contributes to real change through positive citizen engagement with lawmakers, public institutions, businesses and private institutions. Two, to reach a consensus among the conference participants regarding the best available means for re-balancing Indiana's publicly finance system of LTC. Three, to provide the participants with the information they need to engage citizens throughout Indiana regarding the need for a re-balanced long term care system.

Participants

On January 13, 2011 in Indianapolis The Generations Project hosted ***The Good Road Home***, a conference in which seventy individuals discussed solutions to the problems and issues associated with home and community-based services (HCBS) for senior citizens and persons with disabilities.

Participants at January 13 Good Road Home Conference

The participants were persons that had previously participated in education and fact-finding meetings regarding HCBS and related nursing home issues. These meetings were part of the project's Round Table Education Series and were held in communities throughout Indiana from 2007 to 2010. The participants in these meetings

were persons that use HCBS in their daily lives, family caregivers, providers, HCBS professionals, lawmakers, business persons including family farmers, senior leaders, and advocates for persons with disabilities. Over seven hundred individuals participated in these meetings. Among the participants, several individuals attended multiple meetings over the three-year period and developed substantial knowledge regarding HCBS.

The January 13, 2011 participants reflected the mix of persons that had participated in the aforementioned Round Table Education Series meetings. However, ten state lawmakers also took part in the total conference activities as did Kathy Leitch, the former Assistant Secretary, Aging and Disability Services Administration, Department of Social and Health Services for Washington State.

Findings

From 2007 through 2010, seven hundred Hoosiers took part in the Round Table Education Series (RTES). The Generations Project produced a series of reports during that time including *Lessons from Home* and *Lessons from Home Applied* [1] that reported on the findings from the RTES. These findings were based on the verbal and written comments of the participants in the RTES that were submitted in local, regional and statewide meetings, and in writing between these meetings.

The findings covered long term care (LTC) reform with a primary emphasis on the need to establish a comprehensive system of publicly funded, consumer defined and driven, home and community-based services (HCBS) throughout the state. HCBS to be provided in this system were to be funded through existing public programs including the Community and Home Options to Institutional Care for the Elderly and Disabled Program (CHOICE), the Medicaid aged and disabled waiver (or A&D waiver), and the Medicaid traumatic brain injury waiver (or TBI waiver). Of these programs, CHOICE is funded entirely by the state of Indiana while the A&D and the TBI waivers are funded by a combination of state and federal funds (one third state, and two thirds federal).

The RTES participants strongly agreed that HCBS should be the state's program and funding priority. The participants also agreed that nursing home care could not improve in Indiana because it was far too expensive per person and far, far too many nursing home beds were certified and filled in the state. In short, the number of nursing home beds and nursing homes was too large to be properly sustained in terms of the quality of care provided to residents. Indiana simply cannot afford its nursing homes.

The RTES participants also strongly agreed that nursing home care is simply the wrong model of care for virtually anyone needing long term care services. Consequently, Indiana's nursing home population should be no greater than 12,000 to 14,000, and probably far, far lower when compared to other states that have already implemented comprehensive LTC systems change based on HCBS.[2]

The participants in the January 13th conference, *The Good Road Home*, reaffirmed the earlier findings of the Round Table Education Series. The Good Road Home participants reached the following conclusions.

Indiana has a Medicaid funding crisis because of its over investment in expensive Medicaid funded nursing home care, and its under invested in high quality HCBS. To solve its Medicaid spending crisis, Indiana should be expanding the use of HCBS while greatly reducing its public nursing home investment by more than 50 percent in the next 3 to 7 years. The state of Washington used a similar strategy to re-balance its long-term care system beginning in the early 1990s. To make these things happen the CHOICE program should be funded at a minimum of $48.675 million[3] per year, and the CHOICE funds that are currently being used for Medicaid match and other purposes should be restored to the CHOICE program. In fact, the participants concluded CHOICE is Indiana's most efficient, care effective, cost effective, and lowest cost long-term care program.

Richard Simmers and Al Tolbert of the Paralyzed Hoosier Veterans in a policy discussion at the conference.

The participants found that Indiana should also greatly expand the use of the Medicaid aged and disabled waiver and the TBI waiver. The savings generated by these programs and CHOICE, as they reduce the need for Medicaid funded nursing home care, should be retained by the state to purchase additional HCBS. By doing this, the state would create within Indiana's existing Medicaid budget a self-funding mechanism for the next several years that would allow the expansion of HCBS without having to spend additional state and federal tax dollars. The emphasis on HCBS would also improve care and health outcomes, the quality of life in the state, and the attractiveness of Indiana to companies with employees and family members with disabilities. Presently, Indiana has a negative image when it comes to taking care of persons at any age with disabilities. This negative image detracts from the state's potential for economic development.

The January 13th participants also concluded Indiana should assist nursing home providers in transitioning to other forms of LTC, including HCBS, through well planned reductions in nursing homes over a period of three, five or even seven years. There was a discussion of financial incentives including buy-outs, assistance in converting to other forms of long term care (specifically, HCBS), marketing assistance, and the use of small houses to replace a portion of the state's existing nursing homes. There was not a consensus that taxpayers should shoulder the burden of these transitions. Participants felt nursing home owners have profited handsomely from their investments in facility-based care, and those investments were and are business decisions. If citizens no longer want to use nursing homes, and if nursing homes are in fact an inappropriate form of LTC for most of the people who are forced to use them, then why should taxpayers be forced to pay for shutting them down?

Participants also discussed Indiana's failure to comply with the provisions of the U.S. Supreme Court decision in the Olmstead case, and the state's consistent failure to follow the policy lead of

the U.S. Department of Health and Human Services (HHS). Since the early days of the administration of President George W. Bush, the HHS Centers for Medicare and Medicaid Services (CMS) has consistently pushed states to grow HCBS as a means to save Medicaid dollars and to produce better health outcomes. The mechanisms used by CMS have included Money Follows the Person (MFP) grants to give states financial incentives to move people from nursing homes back into community-based care settings. Indiana has had an MFP grant for several years and has done a very poor job of transitioning people out of nursing homes with those federal dollars.[4]

Representative Tom Knollman addressing conference participants.

The participants also noted Indiana continues to invest an overwhelming percentage of its total long term care dollars in nursing homes: 79.9 percent of all Medicaid long-term care dollars.[5] The participants in the January conference concluded Indiana is at great risk of having an Olmstead-like legal action brought against it. In fact, the U.S. Department of Justice has warned states it is prepared to take legal action in order to bring about compliance with the decision of the U.S. Supreme Court in the Olmstead case.[6] Participants in the conference made it clear that access to appropriate HCBS was becoming a matter of civil and human rights.

The conference participants also found Indiana is doing a poor job in serving people with brain injuries regardless of the source of those injuries. War, car accidents, tumors and cancers, other diseases, industrial and farming accidents, athletics, domestic violence, falls by the elderly and persons with disabilities, and many other factors cause brain injury. But in Indiana, the state continues to block access to publicly financed home and community-based services and continues to drive people out of state to get services if they have brain injuries.[7] The participants concluded Indiana needs a thorough and thoughtful study of the full array of brain injury services currently available or not available in the state. Those would include trauma care, acute care, post acute and life span services, research, education, life styles and prevention. If the state will do these things, many millions of tax dollars could be saved each year, the quality of life improved, and the state's economy strengthened. The participants said this process should start with a study commission that includes persons with brain injury and their family caregivers as well as legislators and brain injury professionals.

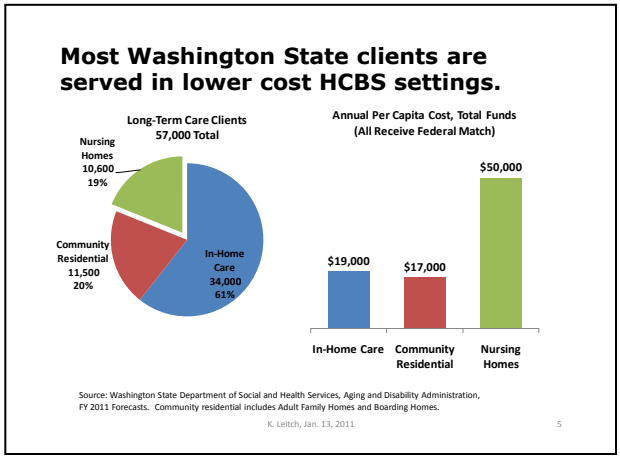
The conference attendees also concluded Indiana's privatized public benefits (or welfare) system that determines eligibility for Medicaid, Temporary Assistance for Needy Families (TANF), and the Supplemental Nutrition Assistance Program (SNAP) continues to perform in a manner that harms citizens including senior citizens, persons with disabilities, and families[8] The failures of the state's Division of Family Resources (DFR) to administer public benefit programs properly means people are denied HCBS through Medicaid waivers and CHOICE because of the continued failure of the private vendors used by the division to process applicants. Sadly, area agencies on aging, private charities, and providers must continue to use substantial amounts of

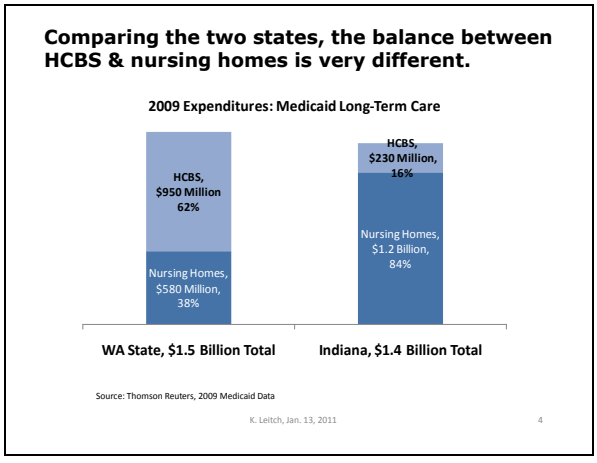
staff time to help enroll qualified and medically at-risk citizens for Medicaid and nutrition assistance because DFR can no longer competently handle these tasks.

Representatives of the Indiana Home Care Task Force Committee on Welfare Privatization Issues that attended the conference suspect the Indiana Family and Social Services Administration may be manipulating the DFR outcomes data that is now being submitted to the federal government. The Indiana data has dramatically improved since 2009, when the state began its so-called hybrid version of welfare privatization. Those improvements, which include substantial drops in errors rates, do not seem to be matched with substantial changes in the skills of the private vendors used by DFR. Conference participants concluded an in-depth third party audit of Indiana's public benefits programs is needed. Members of the Committee on Welfare Privatization Issues, who were all volunteers,[9] helped thousands of qualified and needy Hoosiers get their public benefits restored from 2007 through 2010.

Long Term Care in Washington State and Indiana

Kathy Leitch, a Partner with C.E. Reed and Associates and the former Assistant Secretary for Aging and Disability Services for Washington state, was the featured presenter at the conference. Kathy spent nearly two decades directing publicly funded HCBS programs for Washington. In her presentation, Kathy noted that Washington state has a population of 6.6 million people but only has 10,600 individuals per day in Medicaid funded nursing home care. This is true because Washington has aggressively expanded its use of HCBS and has achieved substantial savings in taxpayer dollars through expand home and community-based services and to reduce the use of nursing home care. Washington uses a variety of incentives to assist nursing home owners to convert to other forms of long-term care or to simply go out of business. Washington also uses the savings generated in its long-term care system to improve the quality of direct care in its remaining nursing homes.



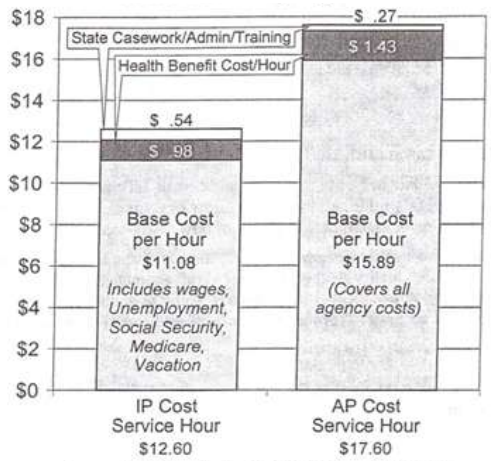


By comparison, Indiana has a population of nearly 6.4 million people and a Medicaid nursing home population of over 28,500 individuals per day. With virtually identical levels of total long term care dollars, Indiana serves only 14,000, or fewer, individuals per day through its CHOICE and Medicaid aged and disabled waiver programs while Washington serves 45,000 persons in comparable home and community-based services. It is no surprise to learn that Washingtonians have better health care outcomes than Hoosiers.

Individual Providers in Washington and Indiana

Washington state makes extensive use of individual providers as well as agency based home care providers. Indiana makes little use of individual providers and that failure is a major contributor to the high cost of Medicaid waivers in the Hoosier state. According to a 2007 legislative study commission in Washington, that state saves on average $5.00 per hour of service when utilizing individual providers for home care services: $12.60 vs. $17.60. The Washington legislative study also found the quality of care delivered by individual providers and client satisfaction to be high. For Indiana to provide high quality and affordable home care services through the CHOICE and Medicaid waiver programs it must allow consumers easy and equal access to individual providers and agency based providers. Both approaches must be vital components in any system of long term care used in the state.

Comparative Total Hourly Cost to the Washington State of Individual and Agency Providers



Joint Legislative Audit and Review Committee, State of Washington, 2007

Long Term Care in the U.S. and Indiana

Indiana ranks 48th in the U.S. in the provision of HCBS as a percentage of public dollars spent on long term care. That places Indiana near the bottom of the pile. Unfortunately, that is not merely a number. It is a representation of human lives….what is actually happening to our fellow citizens in our state.

Indiana ranks 9th in the number of nursing home beds available per 1,000 people over the age of 65. Indiana provides 62 beds/1,000 people over the age of 65. The national average is 45 beds/1,000 people over 65. Thirty-five percent (35%) of Indiana's nursing facilities were cited for deficiencies for actual harm or jeopardy of residents, which ranks the state as the 5th worst for these deficiencies.[10]

Indiana ranks 36 out of 40 states in the percentage of Medicaid dollars spent on HCBS vs. institutional care according to a 2009 Thomson Reuters research paper. As previously noted in this report, 79.9 percent of all public funds spent in Indiana for long term care go to nursing homes. Only a small amount is used for home care and related services. As a state that takes pride in its hospitality, Hoosiers should be shocked and saddened by these numbers. They are a harsh baseline measure of how we treat senior citizens and persons with disabilities.

Recommendations

In the executive summary at the start of this report fifteen specified steps and/or actions are identified. ***These are actions that Indiana should take now***. These are common sense actions to improve the quality of life for all Hoosiers, save enormous sums of taxpayer dollars, and boost the state's economy. These are actions that would allow senior citizens, persons with disabilities, and family caregivers to live with substantial dignity and freedom. These recommendations should be implemented now: quickly, competently and thoroughly. Doing less than this is not acceptable.

Doing less is what Indiana has done in the past and is doing presently. Doing less is a measure of how we value ourselves as a society and as a state. It is a sad measure. At the January 13th conference people said clearly and emphatically that caring and doing more is not just common sense: it is also smart financially. Caring for our fellow human beings with disabilities, joining with them in partnership as family, neighbors, workers, professionals and fellow citizens to bring full independence and vitality to their lives is *the good road home* for all Hoosiers. Let's begin the journey. Let us follow the good road home.

Endnotes

1. *Lessons from Home* (2008) and *Lessons from Home Applied* (2010) can be viewed on The Generations Project website at www.generationsproject.org.
2. The calculation is an estimate based on outcomes in Washington when compared with Indiana. Both states have populations that are nearly identical in size but Washington has a fully re-balanced long term care system and better overall health care indicators and outcomes in its population.
3. The total annual funding level that has been traditionally used by the Indiana General Assembly for the CHOICE program.
4. As of June 2011 the Indiana Division of Aging reported the state had only transitioned 305 people out of nursing homes using the federal Money Fellows the Person grant.
5. As calculated by Kathy Leitch of C.E. Reed and Associates in preparation for the January 13, 2011 conference, *The Good Road Home*, hosted by The Generations Project. The Indiana Division of Aging has publicly said the percentage of the state's long-term care budget spent on nursing homes is near 75 percent. However, advocates for senior citizens and persons with disabilities have reported the percentage spent on nursing home care to be 90 percent or higher. The differing numbers appear to be based on different sets of data. Bottom-line, Indiana does a very poor job of investing in home and community-based services.
6. As reported by Kathy Leitch at the January 13, 2011 conference.
7. Though the Medicaid program Indiana pays for out-of-state treatment for people with brain injury, primarily at rehabilitation centers in Illinois and Michigan, because the needed services are not available in the state. The costs are thought to range from $14,000,000 to $18,000,000 per year. See page10, *Lessons from Home Applied*, The Generations Project (2010).
8. See pages 32 –34, *Lessons from Home Applied*, The Generations Project (2010).
9. The volunteer members of the Indiana Home Care Task Force Committee on Welfare Privatization Issues included former welfare caseworkers, former welfare administrators, elder law attorneys, independent case managers, executives of non-profit corporations, a township trustee, farmers, and a retired banker.
10. The sources cited in this section are the following:

    Houser, Ari, Fox-Grage, Wendy, Gibson, Mary Jo, *AARP Across the States: Profiles of Long-Term Care and Independent Living: Indiana, Eighth Edition.* AARP Public Policy Institute, 2009.

    Steve Eiken et al., "*Medicaid Long-Term Care Expenditures in FY 2009*", Thomson Reuters, August 17, 2010

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